

# The Advocacy initiatives of The Leprosy Mission, Myanmar (TLMM)

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*Working towards a barrier free Myanmar*

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# Background to TLMM

- TLM in Myanmar over 100 years
- Between 1874-1917 TLM extended work across 12 countries in Asia focussed on care & medical support
- Cure Era from 1941 Dapsone, (1981 MDT): efforts to eradicate leprosy led to huge reduction but still ¼ million new cases/year & around 4 million disabled by leprosy



# TLMM's move to Double Mainstreaming

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- Less cases of leprosy
- Only 82 people per km<sup>2</sup>
- People affected by leprosy scattered - 90% outside 'leprosy villages'
- From 2005, a new strategy was implemented, which *sought to expand both the geographical and methodological scope of TLMI's work in Myanmar by integrating leprosy related rehabilitation into general disability rehabilitation, and in turn to integrate that into the mainstream disability movement.*



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# TLMM's move to Disability Rights-based Approach



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- Previously, 'TLM's methodology and practice was based on the medical/individual model of disability. This does not look at rights and issues related to barriers to inclusion etc. Because of our history and because of our staff/skills base being mainly in the medical/para-medical professions, concentrate on medical and physical rehabilitation, mostly using institutional-based methodology.' Dr Mike Griffiths

# TLMM's move to Disability Rights-based Approach

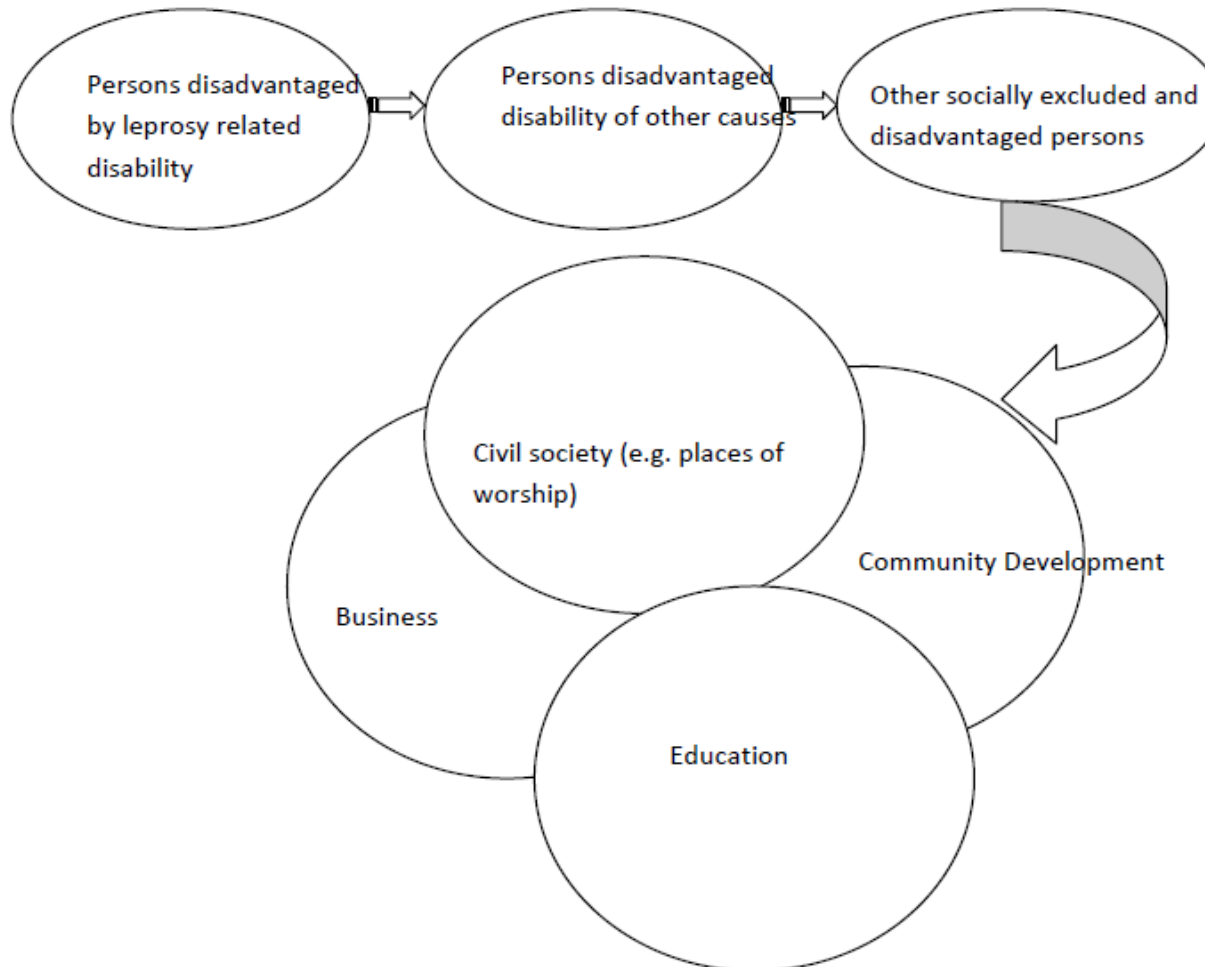
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- Meta Goal: 'People disadvantaged by disability due to leprosy and other causes will be empowered to take control of their own situation to participate in and contribute to society as equals'. 2006
- Organizational goal: ' To be a leading voice in Myanmar in addressing the needs of those socially excluded by physical disability (leprosy and non-leprosy related) or by stigmatization.
- This will take the form of specific advocacy, local aid and development, and research into disability and stigma.'

# TLMM's move to Disability Rights-based Approach





# TLMM Rights-based Approach

## Saturation Right (incorporated into ALL activities)

**Right: I have a right to participate in decisions made about me**

**Methodology:** participative approach through collaboration with DPO, community groups, active support of self-help groups, participatory planning and evaluation, use of narratives  
**Mode of delivery:** approach embedded in all projects  
**Outcome measure:** assessment of participation by MSC

**Right: I have a right to support myself and my family and to participate in society**

**Methodology:** integrated socioeconomic rehabilitation & advocacy, mainstreamed approach with local business and development projects  
**Mode of delivery:** MCLH, MCTP, DRC, ESSLM  
**Outcome measure:** EVS, MAO, positive life change (MSC)

People with suspected leprosy

**Right: I have a right to accessible and timely treatment**

**Methodology:** diagnosis and treatment with MDT  
**Mode of delivery:** MCLH clinic  
**Outcome measure:** % completion; %G2 deformity

People with leprosy: after treatment

**Right: I have a right to protect myself from disability due to leprosy**

**Methodology:** POID including reaction treatment, self care and ulcer care  
**Mode of delivery:** MCLH, MCTP, ESSLM, ILEP partnership with NLCP  
**Outcome measure:** ulcer free interval.

Leprosy affected and/or disabled adults and children socially and economically disadvantaged

Leprosy affected and/or disabled adults and children compromised mobility

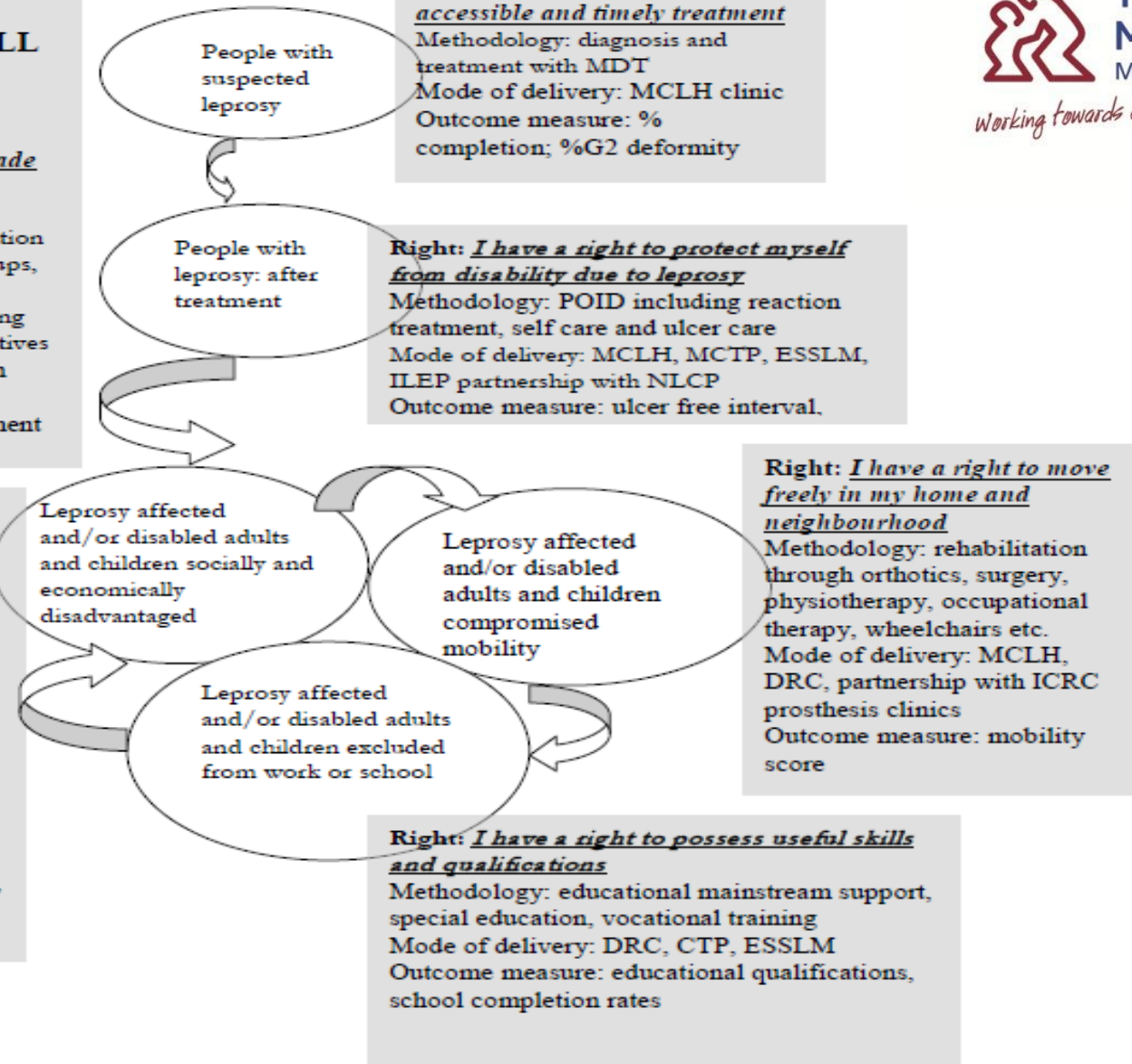
**Right: I have a right to move freely in my home and neighbourhood**

**Methodology:** rehabilitation through orthotics, surgery, physiotherapy, occupational therapy, wheelchairs etc.  
**Mode of delivery:** MCLH, DRC, partnership with ICRC prosthesis clinics  
**Outcome measure:** mobility score

Leprosy affected and/or disabled adults and children excluded from work or school

**Right: I have a right to possess useful skills and qualifications**

**Methodology:** educational mainstream support, special education, vocational training  
**Mode of delivery:** DRC, CTP, ESSLM  
**Outcome measure:** educational qualifications, school completion rates



# Delivery through DRCs

- This ‘double mainstreaming’ manoeuvre was shaped around *Disability Resource Centres*
- 19 DRCs throughout the country from which TLMM provides services & runs its activities: physiotherapy, community based rehabilitation, barrier free intervention, livelihood & advocacy.
- 3 main advocacy projects





# 7-Up Project

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- In 7 states & regions: objectives
  - State and Regional Parliament will recognize importance of and able to implement disability law.
  - Local government (civil service) will have capacity and sensitization towards disability related issues.
  - Local organizations will have recognition and ability to implement relevant aspects of disability law.
  - Local churches will include persons with disabilities in their activities
  - Local communities will include persons with disabilities in their activities
  - Groups of persons with disabilities will be empowered to advocate for their own rights



# Livelihood & Barrier Removal Project



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- Reducing the physical and social barriers faced by 2,000 people with disabilities in seven States and Regions in Myanmar and improving their livelihood
- Livelihood Provision
- Training other NGOs
- Employers Sensitised
- Barriers Removed/Access to markets
- Market initiatives
- Labour Charter development



# Realisation of Disability Rights in Myanmar

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- PwD involved in development of/reporting on disability policy and legislation: National Plan of Action Review, country report UNCRPD.
- Govt officers trained on disability
- Increasing capacity of DPOs
- 'Disability' included in National Census
- Study on SHGs in Dry Zone

# Case Study: Census

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- National Census planned March 2014
- Draft census weak on disability (only 1% PwD recorded in pilot)
- Dr Zaw found out about Washington Group (WG) internationally recognised format for collecting data on disability
- Spoke to DFID, advisor to census, Dept Social Welfare (DSW)
- DSW had already developed a questionnaire with DPOs
- DSW & Census authorities eventually agreed to WG format

# Disability Rights Law

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- Process started 2011
- As Myanmar Focal Organisation on Disability TLMM involved
- DSW didn't involve DPOs/PwDs enough
- Went to Attorney General's office
- Following lobbyists agitating regarding a media law DPOs/PwDs & made a forum, demanded changes
- DSW agreed to many of the proposed changes with compromises by DPOS
- Includes provision that 1% of commercial employers must be PwD & new infrastructure must be barrier free
- TLMM supported both DSW & DPOs, new law expected by end of year (will be first on disability since 1958)



# Hpayachaung Community Bridge

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- A member of community who wanted to help PwD in his village approached TLMM
- TLMM visited met 2 CBOs (mostly young people), authorities & chief monk (Buddhist)
- TLMM gave 2 days training, then organised discussion
- Committee (mostly CBO members formed)
- Community donated half the cost (including large donation from the monk) & equipment
- Benefited the whole community!

